



Kansas Governor's Commission on Autism

January 12, 2011

Governor Sam Brownback
Capitol, 300 SW 10th Ave., Ste. 212S
Topeka, KS 66612-1590

RE: GOVERNOR'S COMMISSION on AUTISM 2010 REPORT and RECOMMENDATIONS:

In 2010 the Governor's Commission on Autism recognized the need to develop a state plan for Kansas. The focus of our efforts was to develop a comprehensive state plan to meet the needs of individuals with Autism Spectrum Disorder throughout the lifespan. The Kansas Governor's Commission on Autism State Plan further reveals a map of what has been accomplished across Kansas and what Kansans still need do to assure that all Kansans with Autism Spectrum Disorder and their families have equal access to opportunities and resources.

Autism in America:

In **1987** approximately **15** in every **10,000** children were diagnosed with autism. In **1998** resources from the Centers for Disease Control indicated that from 1987 through 1998 the incidence of autism increased **633%**, and determined that **1** in every 500 children were diagnosed with autism. In **2007** the Centers for Disease Control reported that **1 in every 150** children were diagnosed with autism, the ratio of boys to girls was 4:1. December, **2009** the Centers for Disease Control reported the number of children diagnosed with autism had **increased to 1 in every 110 children, 1 in every 70 boys**. Today, In America 1%, of children are diagnosed with an Autism Spectrum Disorder.

<http://www.cdc.gov/ncbddd/autism/data.html>

<http://pediatrics.aappublications.org/cgi/content/abstract/peds.2009-1522v1>

<http://www.autism-society.org/site/News2?page=NewsArticle&id=15065>

Autism in Kansas

The Governor's Commission on Autism was established to monitor and report to the Governor, the current state and the future needs of Kansans with Autism. The Task Force of **1987** projected that **3,654** Kansas adults and children were identified with autism. In **2010**, the Kansas University Medical Center, Center of Children's Health and Development reports that **900** inquiries were received from persons interested in an Autism Spectrum Disorder assessment; **600** of the children assessed were diagnosed an Autism Spectrum Disorder. The average age of those diagnosed was four. The Kansas Instructional Support Network's teams report approximately **118** requests for assessments of children throughout Kansas; **88** children assessed or **75%** received a diagnosis of Autism Spectrum Disorder.

Serving the Southeast region of Kansas; Parsons State Hospital and Training Center formally started an Autism Clinic two years ago and dedicates one day per week to autism evaluations. The PSHTC Autism Clinic received **104** referrals and completed **90** autism evaluations. The clinic reports a **17%** autism diagnosis rate.

In **March, 2010**, the Kansas State Department of Education reported **2545** students with Autism.

47.6% of students reported to KSDE with ASD live in these suburban areas.

USD 202	Turner	20	USD 229	Blue Valley	194
USD 233	Olathe	165	USD 259	Wichita	237
USD 305	Salina	49	USD 308	Hutchinson	34
USD 489	Hays	22	USD 497	Lawrence	126
USD 500	KCK	94	USD 501	Topeka	95
USD 512	SMSD	176			

Total: 1212

1,333 students live in rural areas of the state outside of these areas (Roughly **52%** of students reported to KSDE with Autism Spectrum Disorder.)

In 2000, 710 or 1.16% of children ages 3-21 who received special education services in Kansas have autism. In 2008-2009, 2,097 or 3.19% of children with disabilities ages 3-21 who received special education services had autism.

Table 1-1: IDEA Part B - Children with Autism in Kansas for 1999-2000 and 2008-2009
(Child Count by Age Group)

	Child Count in 1999-2000	Child Count in 2008-2009
Age 3-5	87	216
Age 6-11	424	942
Age 12-17	169	810
Age 18-21	30	129
Age 6-21	623	1,881
Age 3-21	710	2097

Source: Reported by the State of Kansas in accordance with Section 618 of IDEA to U.S. Department of Education, Office of Special Education Programs

Table 1-2: IDEA Part B - Children with Disabilities in Kansas for 1999-2000 and 2008-2009
(Child Count by Age Group)

	Child Count in 1999-2000	Child Count in 2008-2009
Age 3-5	7,728	9,896
Age 6-11	25,892	27,183
Age 12-17	24,910	27,750
Age 18-21	2,737	2,901
Age 6-21	53,539	55,834
Age 3-21	61,267	65,730

Source: Reported by the State of Kansas in accordance with Section 618 of IDEA to U.S. Department of Education, Office of Special Education Programs

http://www.easterseals.com/site/PageServer?pagename=ntlc8_2010_state_autism_profiles_kansas

http://www.autism-society.org/site/DocServer/Autism_Kansas_v3.pdf?docID=9846

<http://www.thoughtfulhouse.org/tech-labs/disabilities/autism.php?s=KS>

Kansas Action and Accomplishments:

In developing the State Plan, the Governor's Commission on Autism recognizes the activities and efforts to support individuals with Autism Spectrum Disorder that are occurring across Kansas. These advocacy actions and accomplishments demonstrate an atmosphere of collaboration and accountability.

Autism Awareness: Kansas continues to be diligent in statewide action and achievements. There has been substantial work in improving Autism Awareness and in providing training on early identification and diagnosis. Collaborative efforts in 2008 and 2009 provided regional training for school and 0-3/Tiny K teams in 63 of the 105 counties throughout the state. Autism Diagnostic Teams (ADTs) were trained to identify and complete assessments on children suspected of having an autism spectrum disorder. Local physicians, school psychologists, special education teachers, speech pathologists and occupational therapists, work within their area schools and communities raising awareness and dissemination of "Learn the Signs, Act Early" information. Advances towards improving diagnostic capacity through statewide Outreach clinics; improving the use of technology and Tele-medicine; increased training opportunities for educators; coaching in transition assessment; KISN trainings on EBP; and the Summer Institute on Structured Teaching are some of the many examples of ongoing efforts across Kansas, to raise awareness of autism spectrum disorders.

Advocacy Efforts: Advocacy is a constant for parents, professionals and individuals with an Autism Spectrum Disorder. The Autism advocacy efforts of members of the Commission can be directly connected to an increase in awareness and improved outcomes in reducing the waiting periods for diagnostic assessments. In the past five years diagnostic appointment waiting periods have been reduced from **2 years to 45 days**. Individual and group advocacy efforts across Kansas have greatly improved educational and professional use of evidence-based practices, diagnostics, parental support, self-advocacy, and current legislative matters. Further, training continues to be made available statewide through conferences that feature experts in the field of Autism.

Legislation designed to improve the lives of those with Autism Spectrum Disorder has bipartisan support statewide.

Kansas Governor's Commission on Autism

<http://www.srs.ks.gov/agency/css/Pages/Autismwaiver/KansasGovernor%27sCommissiononAutism.aspx>

Established by House Concurrent 5071 by the Kansas Legislature in 1987; the Governor's Commission on Autism advises and makes recommendations to the Office of the Governor in regard to matters related to Autism, families with a child with an autism spectrum disorder, and service providers. The Commission consists of 15 members appointed by the Governor.

Kansas Instruction Support Network – KISN <http://www.kansasasd.com>

The Mission of KISN is to support Kansas school districts in building local capacity to serve students with diverse learning needs, through results based professional development training, and technical assistance. KISN maintains a lending library that is accessible online. Autism Diagnostic Teams have been developed through a two day training that is offered two times a year. Provided free of charge to school districts in Kansas. KISN provides ongoing training for parents and educators through the [KISN Training Series](#) that is presented through the ITV Network, broadcast to 13 regional sites statewide. The training series is developed each year with the assistance of the Autism Consortium that includes faculty from the Fort Hays State University, Pittsburg State University, University of Kansas, Emporia State University and Wichita State University. Those universities offer three hours of graduate credit for the completion of the

training series and additional assignments. For those who wish to attend the training sessions without earning graduate credit, the sessions are provided without charge; those who wish to earn credit are responsible for the costs associated with that endeavor. KISN staff is available to provide direct observation and consultation for individuals students when the local school districts have exhausted their resources. Regional Autism Consultants (RACs) are also able to provide services if a KISN member isn't available. The Regional Autism Consultants are full-time employees of school districts throughout the state. KISN purchases days from their contracts in order to share their expertise to other districts. When requested members and RACs also provide districts with training tailored to meet their specific needs.

Center Child Health and Development – CCHD - Kansas University Medical Center

<http://www.kumc.edu/cchd/>

Advancing the health, development, and well-being of children at risk or who have developmental disabilities and supporting their families through the provision of: (1) exemplary clinical service; (2) interdisciplinary leadership training; (3) outreach training and technical assistance and (4) collaborative academic research is the Mission of the CCHD.

Children seen at the CCHD often present with developmental and/or behavioral challenges that are challenging and puzzling to families, communities, and schools. The clinicians at the KU Medical Center CCHD evaluate and diagnose children who may have developmental disabilities (DD). In addition to diagnostic services, the CCHD works with families, schools, and communities to develop treatment plans. The goal at the CCHD is to accurately diagnose the child and recommend the most effective treatments.

The challenges, as well as the strengths, of the children served by the CCHD are assessed in order to understand the diagnostic picture. An interdisciplinary team approach to the diagnosis of DD means that children and families have access to professionals in a broad range of treatment areas.

Pittsburg State University Autism Certification

<http://kcmetro.pittstate.edu/home/academic-programs/autism-certificate.dot>

The 15-18 hour non degree program is designed to certify that participants have specialized knowledge and skills in working with children with autism. These classes are available online and via IDL offered at the KC Metro Center.

Kansas Center for Autism Research and Training Center - KCART <http://kcart.ku.edu/>

The Kansas Center for Autism Research and Training (K-CART) at the University of Kansas, established in 2008 with private and public funds, is a new multidisciplinary center that promotes research and training on the causes, nature and management of autism spectrum disorders (ASD). Committed to the highest standards of scientific rigor, K-CART will generate new scientific discoveries about ASD, disseminate research-based practices by training professionals, practitioners and families who serve children and adults with autism, and provide clinical services through the Center for Child Health and Development at the University of Kansas Medical Center.

Kansas Home Community Based Services Waiver (HCBS): Autism Waiver

http://www.srskansas.org/hcp/css/Autism/CMS_Approved_Autism_Waiver_application_9.25.07.pdf

Current Autism Waiver Application Map: http://www.srs.ks.gov/agency/css/Documents/Autism/Autism_Map.pdf

Current Autism Waiver Providers: http://kansasearlyautism.org/information/locator_map.aspx

Approved in September 2007 and effective January 1, 2008, the Autism Waiver provides support services to caregivers of a child with autism spectrum disorders and early intensive intervention treatment for children with autism. Children may enter the program at the age of diagnosis through five years. In order to be eligible, the child must be diagnosed by a medical doctor or Ph.D. licensed psychologist using an approved autism screening tool (e.g., CARS, GARS, ADOS, ADI, ASDS) and evaluated for a Level of Care Determination to assess functional eligibility. Services are provided for three years and may be extended for one year if deemed medically necessary by approval of the review team. Covered services include consultative clinical and therapeutic services by an autism specialist, intensive individual supports, respite care, parent support and training, and family adjustment counseling. Commission advocates and Kansas Legislature passes Kansas Autism Waiver. Twenty-five slots were funded in 2007. In 2008, The Kansas Legislature approved funding for an additional twenty additional slots. Currently 254 Kansas children are on the waiting list for the Waiver. In 2010 the Autism Waiver was renewed and the addition of communication skills was included in covered services.

Kansas Autism Insurance Mandate House Bill 2160

<http://www.kslegislature.org/bills/2010/2160.pdf>

On March 16, 2010 a compromise bill was introduced as HB 2160. Because Kansas law requires that any health insurance mandate first apply only to state employees in the state employee health plan for at least one year in order to assess cost and utilization of the service, the insurance coverage for autism services first will be such a “pilot project.” The benefits of HB 2160 apply only to members of the Kansas State Employees Health Plan (SEHP) who are less than 19 years of age. Covered services include diagnostic evaluation, Applied Behavior Analysis and any treatment “prescribed or ordered by a licensed physician, licensed psychologist or licensed specialist clinical social worker.” Approved treatments must be “recognized by peer reviewed literature as providing medical benefit to the patient based upon the patient’s particular autism spectrum disorder.” The legislature will determine at a later date if the mandate should be expanded beyond the pilot project. HB 2160 passed the full Senate and House, and on April 19, 2010 Governor Parkinson signed the bill into law.

GOVERNOR’S COMMISSION ON AUTISM RECOMMENDATIONS:

1) Regional Autism Centers/Systems

The Governor’s Commission on Autism remains steadfast in our recommendation and goal to establish regional diagnostic and outreach centers. The Commission believes building regional and local capacity across Kansas will provide the best possible outcomes for individuals with autism and their families. All regions of the state of Kansas require increased access to qualified diagnostic services, treatment and intervention providers.

2) Seamless Transition Throughout the Lifespan

The Governor’s Commission on Autism recognizes that individuals with autism and their families require a seamless transition throughout the lifespan. The journey of autism is a continuum of transition. The Governor’s Commission on Autism identifies that individuals and families must be provided support to navigate through diagnosis; early childhood; Early Childhood 0-5; school age through age 21; transition to adult; and geriatric life. Services for Kansans affected by autism spectrum disorder need to be provided throughout the lifespan. Throughout the life journey, individuals with autism and families require access to family support, counseling and respite care services. These services and supports should be completely individualized and integrated and

occur along a continuum services provided to our children, adults and families, throughout the entire state of Kansas.

Developing Policy and Autism Awareness Adult Population

The Governor's Commission on Autism recognizes the need to establish policies to meet the needs for the rising population of adult individuals with Autism Spectrum Disorder. Our children grow up and seek independence and engagement in meaningful activities. Adults with Autism Spectrum Disorder desire to be productive, contributing members of their community. The Governor's Commission on Autism believes and makes recommendation to empower individuals with Autism with the right of knowledge and accessibility to opportunities for full participation in education, adult services, employment and community involvement. Additional independent living and employment opportunities throughout the state of Kansas are recommended for transitioning adult population.

- a. <http://www.mandysfarm.org/index.html>
- b. <http://www.kansas.com/2010/09/02/1474579/cartridge-king-helps-disabled.html>
http://www.usatoday.com/news/education/2008-07-08-autistic-college_N.htm
- c. <http://www.ncset.org/>
- d. <http://www.srs.ks.gov/agency/css/Documents/Provider%20Lists/Licensed%20CSPs.pdf>

3) Supporting Federal Legislation

The Governor's Commission on Autism supports the re-authorization of the Combating Autism Act. The original Combating Autism Act of 2006 was a bi-partisan effort that expanded federal investment for autism research through NIH; services, diagnosis and treatment through HRSA; and surveillance and awareness efforts through the CDC. In total, CAA authorized \$1 billion over five years, thereby having increased federal spending on autism by 50 percent. As part of the negotiations on the bill, however, an FY11 sunset provision was included on all authorizations. As a result, some existing federal efforts through NIH, HRSA and CDC would cease to exist in the coming fiscal year without any action. This reauthorization bill will not only extend these important authorizations, but also make exciting investments in service-related activities and create a new National Institute of Autism Spectrum Disorders within the NIH.

4) Support Funding 0-3 Early Childhood and Special Education

The Governor's Commission on Autism recognizes that the increased number of children diagnosed with Autism Spectrum Disorder makes further demands on our educational systems, and that increased funding subsequently needs continue. The gains made in childhood development awareness and early diagnosis also has increased the enrollment in 0-3/Tiny K programs. Funding is requires to be at a level commensurate with the needs of the child. Funding is not the only barrier in Kansas, our biggest hurdle is overcoming a shortage of qualified professionals. Resources need to be directed towards the development of talent in the area of teacher education , and specialized educational therapies such as Speech and Language Pathology and Occupational Therapy. Funding levels also affects Kansas' ability to recruit and retain special education and allied health professional. Kansas currently maintains highly recognized training programs.

5) Kansas HCBS Autism Waiver

The Governor's Commission on Autism recognizes that currently **254** Kansas children are on the waiting list for the Waiver. The number of children placed on waiting list for the Autism Waiver has remained consistent. Currently, **132** children have aged off the proposed Waiver recipient list without having received services; an additional **89** children will age out in 2011. The intent of establishing the Autism Waiver was to provide early intervention services. The Governor's Commission on Autism recommends full funding of the Waiver. Early intervention services covered by the Waiver should serve the individual needs of the child. Occupational therapy should be included as covered therapeutic services. Furthermore, substantial efforts must be accomplished to serve children throughout the state. Rural areas of Kansas have a woeful of lack adequate medical and professional providers trained in autism spectrum disorders. The Commission thus believes and makes the recommendation that training, recruitment and retaining these professionals in these areas must be prioritized.

6) Kansas Autism Insurance

The Commission on Autism recognizes and supports legislation that would expand required health insurance coverage for autism spectrum disorders (ASD) to all fully funded policyholders in Kansas, and to increase coverage limits to be more consistent with that offered under existing Missouri law (i.e. HB 1311). Existing Kansas autism health insurance legislation (i.e. HB 2160) only applies to members of the State Employees Health Plan (SEHP). Less than 2% of children with ASD in Kansas are members of the SEHP. Furthermore, the cumulative financial caps on coverage imposed by Kansas law are among the lowest in the country and are considerably lower than in Missouri. The difference in scope and limitations of mandated coverage between Kansas and Missouri is creating incentive for Kansas families to move across the state line in order to get coverage for autism-related services. The disparity between the two laws also creates a financial incentive for the large number of service providers who work in both states to preferentially see Missouri children rather than Kansas children with ASD so that they can be reimbursed for their services.

Therefore, in addition to the fact that Kansas children with ASD will receive inferior services relative to their neighbors in Missouri, Kansas is also losing tax dollars to Missouri as result of inadequate autism health insurance legislation in Kansas.

<http://www.house.mo.gov/billtracking/bills101/biltxt/truly/HB1311T.htm>

The advocacy efforts throughout the state have demonstrated the enduring character of Kansans. The Governor's Commission on Autism has applied Kansas determination and leadership to develop the Governor's Commission on Autism's State Plan. Continued advocacy action and demonstrable accomplishments are necessary to do what is right for Kansans. Implementation of the Governor's Commission recommendations will advance the best possible outcomes for Kansans.

Respectfully Submitted:

Jeanie Zortman, Chair

Kansas Governor's Commission on Autism